

## AFASTANDO AS SOMBRAS DA HANSENÍASE NO JARDIM SÃO MARCOS, CAMPINAS, SP, PELO TEATRO DE SOMBRAS

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*Removing the leprosy shadows in São Marcos quarter, Campinas, Brazil, by shadows theater.*

*Apartando las sombras de la lepra nel barrio Jardim São Marcos, Campinas (SP), como parte del teatro de sombras.*

### RESUMO

Considerando a inserção da equipe multidisciplinar no Sistema Único de Saúde e a experiência do Grupo de Saúde Coletiva e Atividade Física, propôs-se investigar: i) aplicação do Teatro Interativo de Bonecos no estímulo à procura pelo serviço de saúde pelo diagnóstico precoce de hanseníase e ii) decorrências esperadas na Unidade Básica de Saúde. Para tanto, realizaram-se apresentações para 207 crianças e adolescentes, de ambos os sexos, do bairro São Marcos, periferia de Campinas, SP. Buscou-se explorar o impacto dessa intervenção em dois planos complementares: o acompanhamento institucional se deu através de contactos sistemáticos com o Centro de Saúde local; no âmbito participativo, entrevistaram-se vinte protagonistas, alocados pelos critérios de intencionalidade e acessibilidade e considerados segundo o suporte metodológico da Análise do Discurso. Observou-se, em síntese, que, apesar do atingimento dos objetivos e da avaliação externa positiva, mudanças significativas na Saúde e na Sociedade demandam serviços acessíveis e resolutivos de atenção permanente.

**Palavras chave:** Hanseníase; Educação em Saúde; Teatro Interativo .

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### ABSTRACT

Considering multidisciplinary team acting in Brazil's Health Unique System and the experience from Unicamp Collective Health and Physical Activity Group, the purpose of this study is: i) to apply the Puppets Interactive Theater to stimulate people to search health care by early diagnosis of leprosy; and ii) to evaluate expected effects at Health Basic Unit. For this, theater shows have been presented to children and adolescents, of both sexes, in the district of São Marcos, in the city of Campinas, SP. This intervention impact was analyzed in two investigation complementary plans: institutional follow-up was carried out through systematic contacts with local Health Center; at personal level, participants have been interviewed, being allocated according to intentionality and accessibility criteria and considered following Discourse Analysis methodological support. To conclude, issue involving professionals skills and permanent Health Local Services is pointed out.

**Key words:** Leprosy; Health Education; Interactive Theater.

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## RESUMEN

Considerando la inserción del equipo multidisciplinario en el Sistema Único de Salud (SUS) y la experiencia obtenida por el Grupo de Salud Colectiva y Actividad Física, se propuso investigar: i) la aplicación del Teatro Interactivo de Muñecos en el estímulo para que las personas recurran al servicio de salud y se haga posible el diagnóstico precoz de la lepra e ii) las consecuencias esperadas en la Unidad Básica de Salud. En ese sentido, se realizaron presentaciones para 207 niños y adolescentes, de ambos sexos, del barrio São Marcos, en la periferia de la ciudad de Campinas, en el Estado de São Paulo (SP). Se trató de estudiar el impacto de esa intervención en dos niveles complementarios: el acompañamiento institucional se efectuó mediante contactos sistemáticos con el Centro de Salud local; en el ámbito participativo, se entrevistaron protagonistas, escogidos a través de los criterios de intencionalidad y accesibilidad y considerados de acuerdo con el soporte metodológico del Análisis del Discurso. Se verificó, en síntesis, que a pesar de haberse alcanzado los objetivos y de haberse obtenido una evaluación externa positiva, cambios significativos producidos en la Salud y en la propia Sociedad requieren servicios accesibles y resolutorios de atención permanente.

**Palabras llave:** Lepra; enfermedad de Hansen; Educación en Salud; Teatro Interactivo.

## INTRODUCTION

Education in health has always been into a tight questioning, as to its conceptual elements, actions and doings. At the first scope, some issues were outlined, such as excessive individual biologicism and functionalist extraction on the widely hegemonic practice among us: it refers the perspective of understanding and operating the area through unidirectional transmission of information on health-disease-intervention focused on segments, such as contagion, physiopathologic mechanisms, hygienic procedures, personal habits and also, recently, life style, in order to repeatedly and biasedly impact on people's knowledge, attitudes and practices, independently from determining and underlying social facts<sup>1</sup>. In addition, concerns have been raised over operationalization based on authoritarian techniques application by lectures and oral presentations supported by visual resources in order to motivate / excite assistants and spectators by projecting, for instance, instruments such as diapositives and portfolios<sup>2</sup>.

On the contrary, in this project, events aiming at sanitary awareness-raising processes were undertaken<sup>3</sup>, because participants were given multilateral manifestations opportunities, associated to collective moments of ludic and kinetics involvement, full of cultural and social meaning. In this sense, the traditional Shadow

Theater has been adopted to promote the early diagnosis of Hansen's disease. Actually, this form of scenic theater, derived from the classical Japanese art originally called Bunraku<sup>4</sup>, is shared with youngsters from a population of eight thousand inhabitants connected to the sanitary unit where our actions have been taken for several years, especially in the scope of various local educational components<sup>5</sup>.

Although the school is widely known as privileged dimension for educational health practice that can be accessed by the community, it is assumed, in the current terms of rules and practice of Health Promotion, an innovative commitment that goes even further: it becomes a distinguished empowerment locus as Healthy School. That is, it adopts reflective and dialogical strategies on the reality in which it is inserted, providing voice and action to the leading actors of exclusion<sup>6</sup>.

To sum up, considering the concepts above mentioned, this action research aims to concentrate on Health educational tasks which are active and committed with the process of empowerment through early leprosy diagnosis.

## METHODOLOGY

### Methodological Identification

Quali-quantitative procedures were adopted, in agreement with Gunther's (2006)<sup>7</sup> warning that the researcher, as the main actor in the construction of knowledge, "should not choose between one or another method; on the contrary, he should use several approaches, quantitative and qualitative which adequate to the research question". Above all, this can be seen in Minayo's (2006)<sup>8</sup> fundamental thoughts, when the possibilities of methodological combination are outlined, which is shown as a gain in results quality, because

"...more than opposite pairs, qualitative and quantitative methods bring, in different ways, the articulations between singular, individual and collective that are present in the health-disease process. The dialogical interaction between both contributions (not through juxtaposition or subordination of any field) produces an undeniable advance to understand health problems (...). Without this dialogue between the fundamental ideas of each science, practitioners from different scientific traditions will be restricted to the fruitless debates on these or those concepts limits, operationalization conditions or juxtaposition of methods and techniques." (p.75)

Consequently, the support basis for the present study is the Symbolic Interactionism, firstly described by

Blumer (1969)<sup>9</sup>, when he numbered the three aspects of man interaction with the world. The first aspect reveals that human beings absorb the meanings they are offered. The second establishes that meanings come from social interactions with other people, and the third, in its turn, admits that these meanings emerge as they are administrated by the individual from the moment when the relationship with the elements nearby begins. Generally, it concerns the way people learn to attribute meaning to things through social interaction, with modified senses through interpretative process<sup>10</sup>. According to these theoretical assumptions, actions are guided by beliefs, as childhood values introjection is the basic moment, but standards and rules remain all life long, considering participation in new universes, as Berger; Luckmann (1989)<sup>11</sup> claim.

For those authors, this conception reconciles the purpose of freedom of choice and a model for which values are previous to all the other systems: the internalization of decisions taken would always be ruled by incorporations of primary socialization. In comprehensive terms, this view defines the action as a result of the human construction, through interaction and negotiation that occur according to cultural pre-existing criteria. Finally, as we go on, the same patterns on which this practice is based, dialectical reinterpretation and collective reality reconstruction, are influenced and transformed.

## Study Area

The chosen area to accomplish this Project, the São Marcos Complex, in the city of Campinas, state of São Paulo, Brazil, is composed by the districts of São Marcos, Campineiro, Santa Mônica, Recanto Fortuna and Chácara dos Amarais, with 18.809 inhabitants according to 2000 national census<sup>12</sup>. This Complex appeared next to an old slave village as the city was a trade center and it still keeps some historical features from former fights. A battle called Venda Grande, against the monarchic and conservative govern and which took place during a period called Liberal Revolution at the first half of XIX century, also contributed to this image<sup>13</sup>. So, two cities can be found there: the modern one with an extensive technological pole, identified mainly by the presence of modern universities and several plants, and another which is, still nowadays, marked by the slavery icon.

Collective Health, Epidemiology and Physical Activity Group from Unicamp has carried out several studies and interventions in this metropolitan area for some years. These are projects as the one carried out by Campane et al (2002)<sup>14</sup>, together with the local health center, controlling the endemic injury of modernity, the high blood pressure. In this real context, minimizing existent iniquities is being sought, mainly by

the effort of countless local institutions, which aim at responding to dwellers' demands in their several levels since they deal with the worst of conditions in education, sanitation, housing, health and service resources according to 2000 Demographic Census: i) 21% of householders are illiterate women; ii) 13% have received less than a year of formal schooling; iii) 30% earn up to two minimum wages a month and iv) 17% have no income<sup>12</sup>.

Among the initiatives in the region, two of them are outlined as those we keep greater contact with: Vedruna Assistance Center (Centro Assistencial Vedruna) and Campineira Charity (Associação Beneficente Campineira - ABC). The first one, a non-governmental institution which has socio-educational programs for families, was founded in 1993 and belongs to a project network kept by a religious association, "Irmãs Carmelitas de Vedruna". They began their work in Brazil in the 50's and currently are located in the states of São Paulo, Pernambuco, Paraná, Mato Grosso and Minas Gerais, focusing mainly on health and education in outskirts areas<sup>15</sup>. In Campinas, they have acted since the 90's.

Founded on June 13<sup>th</sup> 1950, ABC is a non-profitable philanthropic organization which started with a volunteer religious group that decided to create the so-called "baby's basket": they collected clothes, soap and diapers in order to donate to poor pregnant women. As necessities intensified, their office implemented a drug-store, medical and dental out patients facilities, baby clothes sewing workshop, bazaar and offered counseling lectures for pregnant women. In 1979, in Jardim São Marcos district church, free soup distribution to the population was started. Later on, they offered a handicraft course for ladies and daycare for 4 to 6 year-old children. In 1993, it became a complementary educational center for 7 to 14 year-old students. Currently, it provides school remedial work, computer science classes, handicraft, English, music and arts lessons, two daily meals, leisure activities; recreation and ongoing conveyance of citizenship concepts<sup>16</sup>.

## Intervention design

Aiming at achieving the proposed goal, some specific interventions were performed, prominently, updating the technical adequacy of the theater material; meetings, trying to establish an action schedule for the research execution; contact with the local Health Center in order to proceed the monitoring of referral people for the service, visits and agreements with ABC board of directors with the purpose of updating the

schedule. The first management mentioned included the checking out of the chosen puppets, the plot about leprosy, scenic materials (foldable table, towel, wood log and felt bushes) and volunteers for puppet control (including one of us - G.C.C.).

At Vedruna, the procedures started soon enough, with the presentation of: investigation dynamics, information issues on Hansen's disease, the necessity of a place to perform the theater sections and the possibility of referrals. Thus, common interests between the institution and the researchers could be clarified. Through this meeting, it was possible to know the facilities, their activity program and their main events and to have the first moment with the population attended. The project was presented to the organization's educators monthly meeting; only then, the schedule for the puppet theater was known, aiming at intense and ludicrous contacts with the population, which results in transformation and knowledge reframing. This stage was a determinant fact, as from it on all systematization to be followed began.

In a second stage, ABC was contacted because its identity, target audience and activities were very similar to those observed for the previous institution, so the experience could be repeated and more semi-structured interviews with the spectators could be added in order to detect the understanding level achieved, their previous knowledge on the topic and their reactions.

Another key point for the success of this conquered relationship was obtained through the joint work with the district Basic Health Unit in the collection of information about the processing that influences the pursuit for assistance, how the institution is organized to provide this service and what actions are taken on the occurrence of a refusal or abandonment. Thus, the respective board of directors was met and the intentions in perspective were clarified: the subject, leprosy, as well as, the possible target public. Then, a strategy for the diagnosis was established, together with communitarian agents and attendants aware of the project and previously oriented about the diseases's specific signals and symptoms so that they could take suitable measures. There was priority, on the very same day, for those who went to the health system for appointments after corresponding home visiting.

Step by step, the following procedures were carried out: meeting with the board of directors to establish the time schedule and the training design; monitoring the communitarian agents, including the ones on fieldwork to understand the actions for which they are responsible; participating in the institution's monthly staff meeting, when the play was performed and doubts were clarified, aiming at better clinical and social awareness of the disease and some adjustments

concerning the referrals and the systematic procedures for such event.

### **Collecting and analyzing data**

The semi-structured interview used entailed questions which, in few words, approached topics on prevention, signals, symptoms, care and cure. The technique used consists of ongoing conversations between interviewee and researcher, according to the objectives established<sup>17</sup>. As recommended, twenty people were interviewed, though this number could vary due to investigation's object and universe, especially if the understanding of meanings, symbolic and classification systems, codes, values, ideas and feelings shall be taken into account. This kind of mediation was chosen because it allows for a better interaction, as information is obtained through "issues or topics previously established according to the core problem"<sup>18</sup>. In order to do so, a flexible plot was made up of four basic questions derived from previous practice, changing if necessary, its content and dynamics.

The interview with children has been more and more adopted. Despite it, some records of non-application were found, due to the consideration of them being "incapable of talking about their own preferences, conceptions and evaluations"<sup>19</sup>. Consistently, this instrument has been used in this population for different Health investigations<sup>20</sup>: the conclusion reached was that, after a faithful relationship and despite their early age, they are able to describe facts, illustrate in details and even relate occasional confidences.

In order to appreciate the collected material, Discourse Analysis (DA) was used as a resource to interpret the texts obtained through records and tab presentations of the absolute and relative frequency distributions, according to Padovani (2001)<sup>21</sup>. DA studying object is the meaning produced by the subject while elaborating speech, intentions and the way it is received by those who read or listen to this speech, thus, providing the possibility of understanding all the dynamics through which oral constructions are elaborated, precisely:

"... problematize the ways of reading the speaker or the reader by posing questions about what they produce and what they hear in different language manifestations. Realizing that we cannot be not subject to language, to its misunderstandings, its opacity. Knowing that there is no neutrality, not even in the most

apparently daily use of signals, entering the symbolic is irredeemable and permanent: we are committed to the meanings. There is no way, but interpret”<sup>22</sup>.

Therefore, it was considered that every saying is a social construction and that it can only be analyzed through its socio-historical context, formal features and the properties of these speeches<sup>23</sup>, which means they are connected to a point of view on the world based on the society in which the speaker lives.

Aiming at obtaining clarity and security in dealing with this technique, the sense of DA can be learned according to the mainstream understandings in the Language Study Institute (IEL) at Unicamp that defines it as “the word in movement”. The meaning of the language or speech is sought, considering that it is always changing. Just “observing the man talking” already provides a constant uneasy sensation. Understanding in itself does not work for DA: what happens is that interpretative aspects are analyzed considering many factors, such as the conditions of discourse production, for instance. That which has “sense and meaning” here and now is far different from what was conceived in the past and it will also be different ten minutes from now. Throughout this process, any gesture of understanding is apprehended before the final “verdict”.

The decisive character of the researcher when using DA is outlined here. He is the one who will choose this or that procedure or question, building up for each new analysis his analytical apparatus. He can – and often does – give a new look to each question or many new aspects of the same question.

### **Ethical aspects**

All the participants of the current research knew about it and their parents signed a document in which they agreed freely and clearly, according to ethical principles of researches with human beings. This project has been approved by UNICAMP Ethical Panel in Research of Medical Science College, under the number 513/2005, as determines Health National Council, outlining the resolutions 196/96 and 251/97.

### **COMMENTS AND RESULTS**

The procedures comprised a group of 207 children and adolescents from 7 to 16 years-old, girls and boys, dwellers of São Marcos Complex, Campinas, SP, and participants of regular activities and workshops developed in a complementary period to classes.

### **Presentations and referrals**

Sessions were carried out at Vedruma according to participants age brackets on different days and times and were previously scheduled depending on the insti-

tution’s interest and availability. The performances were six: three in the morning, two in the afternoon and one during the monthly meeting of the staff responsible for the students in the project. These happened at the institution’s working hours, with no alterations on the program predetermined by the pedagogical coordination. A larger classroom was chosen by the local administration for the performances, where there was enough space for the scenery and for the audience to be as comfortable as possible.

Before each performance, the audience was informed on the topic, the technique used – clarifying the differences between a shadow and a puppet theater – and shown how the puppets manipulation was done. Other points were also clarified, such as their interaction during the play and their participation at the end of the play, that is, they could ask questions about points that they had not understood or had not been mentioned. After this moment, the researchers turned into the characters: Ana Melo and Patrícia. The story is about two old friends who meet after being away for some time (because of the disease, Ana’s parents had left her at her grandparents’). The meeting happens on her birthday. In the course of the story, the characters perform dialogues which, at the same time, clarify issues about the disease and mitigate the prejudice and stigma that surround it. About 20 to 30 minutes later, there was a break for questions, so that doubts could be solved.

Moreover, at this moment, the audience was informed that people who present the disease’s signs, such as red or whitish spots on the skin, cutaneous insensitivity, hair rarefaction and/or neural pain could be forwarded to a medical appointment and evaluation. This procedure happened individually, as generally children came to talk when there were fewer people in the place. Immediately after each of the six performances, nine people asked for guidance in order to get a dermatologic evaluation at the Health Care Center. For subsequent follow up, these requests were subscribed in an appropriate form, where information such as student’s name, age and address were registered.

### **Interviews**

The first results obtained indicated the need to know how much the information conveyed by the puppets was enough and appropriated to promote the results expected. Thus, two performances were implemented, one to each period, totalizing the 87 people attended by ABC. Just as happened at the Vedruna, the previously scheduled plays occurred in normal working hours time; also, the other procedures were carried out similarly to those at ABC. In order to do so, the temple room, located next to the institution building, was used, since its space disposition facilitates communication. At first

the dynamic interviews was explained and the audience was invited to participate. The criterion applied was the availability demonstrated. Participants were attended individually in a room where an identification form was filled out. Then, the questions were made and the answers were recorded and transcribed for later analysis. Twenty participants of ABC activities were interviewed. They were twelve girls and 8 boys from 8 to 11 years-old. Table 1 aims at defining this group better, observing that:

- i) the interviews happened right after the performances and, since the students were allocated by the intentionality and accessibility criteria, ages distributions are presented descriptively heterogeneous;
- ii) most interviewees are in the suitable school year according to their development phase. Only one student had flunked the previous year and was doing it again.
- iii) in general, the children claimed to have small families, as concluded;
- iv) most participants live in up to five-room houses, some in a bit larger ones and;
- v) as to whether the parents are employed, at least one spouse in every household is employed, mothers often as cleaners, housekeepers and nannies; fathers are truck drivers, stonemasons and welders.

As for the initial question, four children said they did not know what the illness was about. A great part of them connected it to "skin spots" and "a sickness transmitted by the air". Some discourses must be outlined, which revealed the ideology that bad things can happen to others, but not to themselves: "this is a spot that others have, if we get closer and breathe, we get it". Some factors out of the real disease context were also noticed; for instance, the relationship between the infection and dust. As for the treatment, many claimed it was necessary "to take medicine", "some pills", "white pills". They also mentioned "seeing a doctor", "a small health care center". There was just a discourse describing the treatment length: "of course there is a treatment...take medicines every day, for six months or a year...it is...only one medicine as far as I understood...". In this case, analogy to other factors were also noticed, when they mentioned the need to "go to the doctor's, then he prescribes an ointment to heal it...".

When asked if they knew someone who had this disorder, they were almost unanimous in saying "no". Just three answers were different: "...the first time I've heard of this disorder was today...", what made us think that these people have not been influenced enough by the advertisements and campaigns. In the following speech, this seems to be different: "

**Table 1** Frequency distribution of interviewees' demographic features.

Demographic Features	Frequency	
	Absolute	Relative
<b>Age</b>		
8 years-old	09	45%
9 years-old.	06	30%
10 years-old	02	10%
11 years-old	03	15%
<b>School Grade</b>		
1 <sup>st</sup>	01	5%
2 <sup>nd</sup>	08	40%
3 <sup>rd</sup>	06	30%
4 <sup>th</sup>	02	10%
5 <sup>th</sup>	03	15%
<b>Household</b>		
02	01	5%
03	05	25%
04	08	40%
05	04	20%
06	02	10%
<b>Rooms in the house</b>		
02	04	20%
03	02	10%
04	05	25%
05	04	20%
06	01	5%
07	02	10%
08	01	5%
09	01	5%
<b>Parents Employment binding</b>		
Mother	06	30%
Father	01	5%
Both	13	65%
<b>Total</b>	<b>20</b>	<b>100%</b>

No, I don't know anybody, but I've already seen a poster in the health care center...". Next thought: "...No! I think I'd be afraid even if I saw somebody, because everybody says it used to be leprosy in the past, then it was really contagious..." in allusion to a mutation process from leprosy to Hansen's disease, where the first one was contagious and the second is not.

To sum up, the prejudice involved in the issue was studied, and the most recurrent point was taken as the search for medical aid. Several people said they "... would send her to the doctor...as fast as possible...". There was a person who stated "...buy her the medicines...or give her the money to buy them herself...". Just one person said "I wouldn't have prejudice; I'd help her in whatever she needed".

### Local healthcare connection

According to the process specificity, this phase of the analysis is implying a new comprehensive investigation

in course inside the research Group, based on the fact that: i) seven out of nine referral people did not continue the process; ii) two were attended in clinical examinations and iii) one case of the disease was identified. On account for two current cases registered in the area and the total number of referrals, a 50% increase in the epidemiometric model prevalence indicator was noticed<sup>24</sup>.

However, discontinuity can be put down to the gap of time between the contact with the theater performances and the actual appointments. This gap of time, of weeks, was not reduced due to the researchers' tasks in their original institutions. The permanent insertion of those professionals in the Health Care Centers is thought to contribute significantly to more expressive results.

Taking into account the experience acquired from the work with communitarian education, allied to the field Group applied activities, closer contact with the local reality can be specified in three basic sequential moments: i) demonstration of working proposals with the institutions involved, University – School – Health Care Center; ii) performance of the puppet theater and iii) training and monitoring health care staff. As for the external evaluation, the project was distinguished in the tribute to Honor and Merit from Paulista Medical Association, Dr. Citizen Prize, São Paulo, SP, 2007.

## FINAL REMARKS

The study has shown viability and adequacy of the methodological qualitative and quantitative procedures in Health Education investigations, respectively by adopting declaration registers and tabs presentations of frequency distributions, both absolute and relative.

The ludicrous and kinetics approaches for Health Education, in this case the Interactive Puppets Theater, were well accepted by schools, even when the topic refers to an illness such as Hansen's disease, whose approach account for widely known barriers.

Attention is drawn to the need of Permanent Health Care System implementation, acting clearly and constantly, aiming at establishing Health Education management persistence.

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